

IDS Working Paper 218

**Childhood vaccination and society in The Gambia: public
engagement with science and delivery**

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January 2004

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Summary

This paper examines public engagement with routine vaccination delivery, and vaccine trials and related medical research, in The Gambia. Its approach is rooted in social and medical anthropology and ethnographic methods, but combines insights from the sociology of scientific knowledge, and ‘actor-oriented’ sociology in development. Current analysis and professional reflection on public engagement with vaccination reflects the concepts and imperatives of health-providing and research institutions. In contrast Gambian parents’ perspectives are couched in very different conceptual and experiential terms, linked to the wider dilemmas of raising infants in a hazardous world. In this context the paper traces parents’ experiences of routine infant welfare clinics and then how they narrate their experiences with two vaccine related studies orchestrated by the Medical Research Council laboratories. A range of contrasts emerges. Whereas health professionals tend to attribute vaccination acceptance to the acquisition of modern scientific attitudes, and talk of “defaulters” as misinformed, parents understand vaccination as a complement to other forms of infant therapy and protection and miss vaccinations through a combination of contingent circumstances and specific worries about vaccination delivery practices. Most parents consider medical research studies less as a separate “scientific” activity than as part of the nexus of normal health practices, and their longer-term experiences and perceptions of MRC as an institution matter more than the aims of any particular study. Whereas medical research staff often perceive public engagement as a matter of understanding or misunderstanding aims and procedures, or of trust and distrust, parental narratives reveal research engagement as a balance of danger and benefit. Study participation depends more on how people’s particular calculus is shaped by social and gender relations, than on issues of knowledge or trust.

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Acknowledgements

This paper has been developed from an earlier draft which was circulated and discussed at a feedback workshop at MRC in September 2003, attended by medical researchers, Gambian health care professionals and representatives from the study communities. It has also benefited from detailed comments by Felicity Cutts, Warren Stevens, Mariane van der Sande, and Sam McConkey. We thank them for their comments, and the communities and health care staff who welcomed us and shared their views with us during the fieldwork. We also thank the Medical Research Council laboratories in Fajara and Basse, and staff of the Gambia Committee on Traditional Practices (Gamcotrap) Bakau for their logistical support. We are grateful to the joint Gambian Government/MRC Ethics Committee for granting ethical clearance for this study, and to the funding organisations which have supported it: the UK Economic and Social Research Council Science in Society research programme, and the UK Department for International Development's Committee on Social Science Research. The views expressed in this paper are those of the authors, and not of these support or funding organisations. Any errors of fact or interpretation are ours alone.

1 Introduction

Worldwide, childhood vaccination epitomises cost-effective public health intervention (e.g. WHO/UNICEF 1996; Cutts *et al.* 1999). The delivery of vaccinations against childhood diseases is widely regarded as a prime area where efficient, effective service delivery is likely to have major positive implications for the poor (World Bank 2004). It is an arena where significant success in meeting international targets is already claimed, and where there is much international investment in new supply arrangements (Heaton and Keith 2002). Vaccination is also an area of increasing scientific and research investment and technological advance, with a significant proportion of this focused on new and improved vaccines against the diseases that are major causes of infant and childhood mortality in developing countries.

While there is currently much international debate concerning the supply of vaccination services and technologies, this working paper focuses on what are sometimes regarded as “demand” side issues. It examines the perspectives of those people who are the assumed users of vaccination services. It examines public engagement with both routine vaccination programmes and service delivery, and with vaccine-related research, focusing on case material from The Gambia in West Africa where both are in train. The paper approaches these engagements from a perspective rooted in social and medical anthropology, but combining insights from the sociology of scientific knowledge and “actor-oriented” sociology in development. From this perspective the research builds on, but also adds to current literatures concerning both the social science of vaccination demand, and medical research in Africa.

This paper presents preliminary findings of an ongoing anthropological research study of public engagement with vaccination services and research in The Gambia, part of a broader research programme on ‘Childhood Vaccination: Public Engagement with Science and Delivery’. One aim of the paper is to inform discussion among collaborators and other interested researchers and practitioners with a view to refining further phases of research, including a questionnaire survey. The project’s long-term aim is to support the development of new, effective approaches to public involvement in vaccine research, delivery and promotion in the context of the rapid proliferation of new vaccines and technologies and evidence of public worries about these.

We begin by outlining the approach taken, in the context of existing literature concerning people’s engagement with vaccination and medical research, especially in Africa. After introducing the study sites, we consider how health institutions and their staff represent the publics they engage with during routine activity or research, showing similarities in such representations linked to institutional imperatives. Current analysis of public engagement with vaccination institutions is, we suggest, premised on the concepts that emerge from such institutional imperatives. Parental perspectives on vaccination and research as they emerge from ethnographic research are couched in very different conceptual and experiential terms, linked to the wider dilemmas of raising infants. In this context we trace how parents experience the routine worlds of the clinics and social interactions there, and then how parents narrate their experiences with two research studies.

A range of contrasts emerges between ways that public engagement is represented in official institutions, and parental experiences of those institutions. First, there is a view current among health professionals that vaccination acceptance is linked to the acquisition of modern scientific attitudes. Yet parents are understanding vaccination as a complement to other therapeutic and protective forms, within their own understandings of how their particular infants develop amidst a range of hazards and uncertainties. Second, although the high levels of vaccination attendance common in The Gambia are often attributed to the positive social aspects of the clinic, this overlooks how it is also a place of worry for most, and exclusion for some, and how this influences patterns of attendance. Third, parents who do not adhere to vaccination schedules are usually categorised as defaulters – a kind of neglectful person. Yet for many, mis-timings arise through exceptional circumstances, which are then compounded by parental concerns with multiple vaccinations, fear of degrading treatment by clinic staff, and other problems in clinic access. Such a train of events can affect anyone.

Similar contrasts are apparent when considering public engagement with research. Importantly, parents consider medical research studies in The Gambia less as a separate “scientific” activity than as part of the nexus of normal health practices, and the Medical Research Council (MRC) which conducts them as one of a number of health providers. It is not that research is not distinguished from treatment (which would be a case of “therapeutic misconception”) but that engagement is with both, together. Knowledge of the aims of a particular study is less significant to people’s decisions about participation than their longer-term experiences and perceptions of MRC as an institution.

Whereas medical research staff often perceive public engagement as a matter of understanding or misunderstanding aims and procedures, or of trust and distrust, parental narratives reveal research engagement as a balance of danger and benefit. In particular, parents balance fears about blood-taking with the advantages of what they perceive as special, free medical treatment for study participants. People’s particular circumstances influence how they weigh up these dangers and benefits, and they lead at times to strong differences between family and community members. Whether or not people agree to participate in research is an outcome of such circumstances and relations of authority, as much as issues of knowledge or trust.

Attention to the life worlds of parents, as we show, questions the salience of categories such as “information”, “consent”, “acceptance”, “refusal” and “resistance” which dominate debates about public engagement amongst research fieldworkers. Indeed, it becomes clear that studies framed in these vocabularies and administrative rationalities can serve to reinforce them, while obscuring subjects’ perspectives further.

2 Understanding public engagement with vaccination and medical research: approaches

While a number of studies in Africa have related the uptake of vaccination to socio-economic, demographic or practical factors (e.g. Brown *et al.* 1982, Eng *et al.* 1991, Gage *et al.* 1997), the emphasis of anthropological work has been on the cultural acceptability both of vaccines themselves, and of different modes of delivery (Greenough 1995). In this respect, and drawing together a programme of social science studies conducted in African countries and elsewhere during the 1990s, Streefland *et al.* (1999) found critical factors shaping vaccination acceptance to turn on (a) how vaccination engages with local knowledge, aetiologies and perceptions of disease, and (b) specific socio-cultural contexts and experiences of interaction between people and health care providers. Together, these factors were taken to constitute “local vaccination cultures” (ibid: 1707), critical to understanding where and for whom vaccination uptake reflects passive acceptance, or active demand; and where non-uptake may indicate active refusal (Nichter 1995).

There is already evidence that in West Africa diverse socio-cultural understandings of the body (e.g. Fairhead and Leach 1996; Madge 1998) and of “folk” epidemiology and immunology provide a variety of interpretative frames for understanding immunisation. For instance, within Islamic understandings immunisations are seen as “like amulets”, offering generalised protection requiring periodic renewal (Imperato and Traore 1969). Equally, discussions within West African vaccination policy reflect on the accessibility, regularity and attitudes of immunization services.

However, reference to other literatures and contemporary social processes suggests the need to expand and enrich this conceptualisation of local vaccination cultures in several ways – by expanding the frame in which “vaccination” is considered, and by reworking “culture”. First, regional medical anthropology highlights a wider variety of forms of knowledge and conceptual understanding linked to “ways-of being” which shape how people might reflect on vaccination, or injections in general (Reeler 2000). For instance “taking injections” can be a means to assert (culturally specific) “modern” identity (Bledsoe and Goubaud 1986; Reynolds-Whyte and van der Geest 1994), but injections can also be a problematic source of ambivalence (Bierlich 2000) and of anxiety – linked, for instance to needles being feared as a source of HIV/AIDS. Where infant vaccinations are concerned, there is a need to understand how people consider broader processes of infant growth, development and wellbeing and the diverse influences on these (Gottlieb and DeLoache 2000), and how vaccinations are thus understood to contribute to (or undermine) these processes.

This emphasis in the anthropology of Africa on how socio-cultural meanings and lifeworlds frame people’s reflections on issues involving technology, echo arguments in the sociology of scientific knowledge as developed mainly in Europe. Starting from a critique of the “deficit model” that assumed that where people do not accept or respond to scientific or technical interventions – including medical ones – as planned, this reflected a lack of knowledge or ignorance, it has been argued and illustrated that public responses actually

reflect distinct forms of experiential expertise (Collins and Evans 2002), knowledge and epistemology (Fischer 2000); and, more fundamentally, different ways of life offering different starting points in thinking about nature and the human (Wynne 2003).

Second, medical anthropology also indicates how people's concerns with vaccination speak to broader notions of socio-cultural and political order, and threats to it (cf. Scheper-Hughes and Lock 1987; Turner 1992). Historical works have documented widespread resistance to vaccination in Africa embedded in cultural and political processes linked to colonisation (e.g. White 2000; Vaughan 1991). More recently, there is evidence of vaccines being understood as sterilising, or as representing coercive state action undermining local or ethnically-based political autonomy (Feldman-Savelsberg *et al.* 2000; Malkki 1995; Talwar and Raghupathy 1989). Such indications underline the need to politicise the notion of "vaccination cultures": to situate vaccination perspectives and rumours amidst particular, cultural and political dynamics extending beyond the local, and to explore how vaccination perspectives are shaped by people's broader political identities and relations with the state as linked, for instance, to ethnicity, migrant or refugee status, or affiliation to oppositional parties.

Third, the notion of vaccination cultures can be enriched by a more detailed and dynamic understanding of the discursive framing, practices and negotiations in micro-interactions between health workers and parents. This is a focus missing from existing anthropological work, yet critical to understanding how people's perspectives on vaccination acceptance are shaped and how they might change. There is little existing ethnographic work on micro-interactions between people and vaccine providers, although some literature has identified the attitudes of (often poorly paid and motivated) frontline staff as a negative influence on vaccination acceptance (e.g. Lovell 1999; Streefland *et al.* 1999). Indeed frontline workers are a relatively neglected category in health systems research more broadly, with sparse existing work focusing mainly on the institutional and economic incentives shaping their activities (e.g. Leonard 2000). Yet actor-oriented sociology in other technology delivery arenas (e.g. agriculture, environment) shows how "interfaces" with frontline workers involve communicative processes, creative exchanges and negotiations of knowledge and meaning which are both framed by, and in turn shape, people's broader perspectives on the technologies, issues and agencies concerned (cf. Long and Long 1994). Such micro-interactions are thus worthy of focused attention as a crucible for the acceptability and effectiveness of different forms of vaccine delivery.

Work on the sociology of scientific knowledge, and on public engagements with science more broadly, would encourage one to locate such micro-interactions within broader questions of people's relations with "expert" perspectives and institutions, and their trust in these (Irwin and Wynne 1996). As Wynne (1992) has argued, publics frequently reflect on institutions involved in delivering technical advice or products on ways which do not just focus on the content of the technology, but on the broader motivations, imperatives and political economy shaping their actions. Equally, these sociology of science perspectives demand of such institutions that deliver scientific and technological advice and products that they are themselves reflexive

about the political-economic and institutional imperatives shaping their work. These institutional contexts and imperatives also shape the discourses that such institutions and their staff adopt about the public, and their knowledge or ignorance (Wynne forthcoming). As we show in this paper, such a perspective is valuable in comprehending how vaccine-providing and vaccine-related research institutions portray their publics in particular ways; and how such discourses in turn feed into shaping the types of engagement that publics have with them.

Nevertheless, and fourth, it is evident that more than ever, people's engagements with vaccine-providing institutions need to be understood in a frame that extends well beyond the local, encompassing much wider, even global dimensions. International travel, communications, media and links with diasporic kin – even for seemingly remote rural African communities – have vastly expanded the field of meanings and experiences which shape people's perspectives on an intervention such as vaccination. People may also reflect on vaccine-providing institutions in frames which link them with known or imagined international processes and political economies. The view among Northern Nigerian publics and politicians that polio vaccine campaigns in late 2003 were an American conspiracy to depopulate the region through sterilisation and by spreading HIV/AIDS is a case in point. More generally, that vaccine provision and vaccine-related research are linked not just to state and nationally-located institutions but to international organisations such as the WHO and UNICEF, to foreign funders and to trans-national pharmaceutical interests, is highly apparent to many African publics. The interaction of historically-embedded cultural perspectives with these emergent globalised fields, and the new forms of public reflection and action that are taking shape in this context, are now of increasing interest in the broader anthropology of globalisation (e.g. Appadurai 2002) and in emergent works which link science studies, anthropology and globalisation (Anderson 2002; Fairhead and Leach 2003; Leach, Scoones and Wynne forthcoming). To date, however, vaccination has not been considered in these terms.

In contrast with the relatively large literature on acceptance or otherwise of medical treatments such as vaccination, and the reasons for this, there has been relatively little work focusing on people's reasons for participating (or otherwise) in medical research. There is, of course, much discussion about medical research ethics in developing country contexts, which addresses, *inter alia*, questions concerning the institutional and political economic contexts for research, questions of poverty and vulnerability, and how research agendas and priorities are constructed (for a recent review see Nuffield 2002). However, questions concerning how publics engage with existing medical research programmes have largely been couched in terms of debates about consent, and particularly the extent to which this is "genuine", that is, properly informed, and voluntary.

These debates around informed consent are linked to the establishment of procedural norms for medical researchers, including international declarations and guidelines (e.g. World Medical Association 2000; CIOMS/WHO 1993), which has been recently reviewed in the UK by the Nuffield Foundation (Nuffield 2002). Debates hinge on several issues. These include whether and how moves towards universal research ethics consent procedures should be tempered by the need to respect local cultural requirements (e.g. Macklin

1999; Christakis 1992). An emergent view is that universal principles can and should be upheld, and that respect for local cultural requirements can be achieved within them (Nuffield 2002). Regarding information, discussions turn on what it is to be fully informed, and conclude that it is necessary for people to know the aims and purposes of a research intervention, and not simply the practices, procedures and medical/material implications of participation in it. Problems in the translation between scientific and local concepts are challenging, but can, it is argued, be feasibly overcome whether through finding bridging concepts, or respectful acknowledgement of contrasting therapeutic knowledges and traditions. These debates fade into discussion of ways that styles of information provision can be tailored to be culturally appropriate; how the length, language and signing of individual consent forms can be adapted and how they may be complemented by other forms of information provision, such as community meetings, radio, theatre and the “traditional” musicians.

Regarding voluntariness, debates have turned first on the ethics of material and other incentives to participate. It is generally concluded that these may be appropriate, but that forms and levels should be determined in conjunction with local ethics committees. Second, there is discussion of the balance between individual and community consent, concluding that while the assent of wider social authorities (local leaders, household heads) may be necessary, this cannot substitute for individualised informed consent by the research subject (Nuffield 2002)

These debates about informed consent focus on the interaction of knowledges within the narrow context of a particular research intervention, in terms rather similar to the notion of “local vaccination cultures”. However, the broader perspectives on people’s engagement with routine vaccination which we have outlined above, also raise a set of parallel questions concerning public engagement with medical research interventions.

First, do subjects interpret research in relation to narrow criteria of consent? Reasoning couched in terms of consent fits logically with the institutional and cultural contexts of medical research interventions themselves, and their administrative and international ethical imperatives. Yet those invited to participate as research subjects may interpret the whole business of engagement within their ways of life and frames for thinking about the body and social relations; for instance in relation to their ongoing concerns and dilemmas in infant care.

Second, how do peoples’ reflections on the political economy of research institutions shape their engagement with them? This has been addressed to some extent in debates around how poverty and the material incentives offered by research institutions play into the dynamics of consent (Nuffield 2002). Again, however, the focus of existing debates is on the particular research intervention, rather than on contextual historical experiences with the institution or indeed (especially where foreign-funded research is concerned), its international symbolism.

Third, and again as with routine vaccination, how do the interactions between people and frontline workers (in this case field researchers) shape people’s views of an intervention? As will become apparent, what

people come to understand of a research intervention from communicative encounters with field staff, or from their reflections on the everyday research practices that they see or experience, may have a rather indirect relationship with formal research procedures or protocols. Yet it is such interpreted practices that build to shape people's understanding of research, and their reasoning about participating in it or otherwise.

Finally, how is engagement shaped by perceptions of the trans-national and global relations of research? Research institutions with foreign origins and identities such as the British Medical Research Council's laboratories in Gambia; funding by multi-national pharmaceutical companies, and international media communications about medical research all create a globalised field which people might reflect on and interpret in the light of their own historical experiences and interpretative frames.

3 Vaccination and medical research in The Gambia

The Expanded Programme on Immunisation (EPI) in The Gambia is internationally recognised for its success in high rates of vaccination coverage, especially by comparison with other African countries. There are, however, pockets of poorer coverage, both geographically and socially, and problems in achieving adherence to recommended timing and schedules. Analysis of these problems has generally concentrated on issues of vaccination supply, such as infrastructure, regularity of transport and delivery, and so on (e.g. Department of State for Health and Social Welfare 2001). There has been less research on issues of "demand"; how parental views on vaccination influence their attendance at vaccination clinics. In the Gambia, a high level of community demand (routinised acceptance) is normally assumed. Yet instances of worry - even of refusal in relation to adolescent tetanus vaccine in the mid 1990s - suggest the potential importance of demand issues.

In The Gambia, there is also a long history of vaccine trials and related research principally linked to the UK Medical Research Council (MRC). MRC in The Gambia is the country's third largest employer, and after 50 years remains the UK's principal public investment in medical research in Africa. Here, the epithet that 'Africa is a laboratory' has more literal meaning. MRC's five field stations house advanced laboratories and orchestrate clinical trials that cover large areas of the country. They focus on malaria, HIV/AIDS, other viral diseases, pneumonia, nutrition, non-communicable diseases, tuberculosis and reproductive health, and are particularly strong in vaccine evaluation. Anthropologists have been involved in many of these initiatives, but none have focused closely on the research process itself and its significance for contemporary Gambian society and its engagement with the wider world.

There are links between routine vaccination and research. Vaccine research programmes have supported routine vaccination infrastructure and supply, and indeed in some cases - such as for the Hib vaccine trials of 1993-95, and the Pneumococcal Vaccine Trial of 2001 - 2004 - have been integrated with EPI. Questions also arise around whether and how people differentiate between research and routine vaccination, and whether attitudes to trials might influence demand for routine healthcare - and vice versa.

MRC research depends on good relations with Gambian society. There is a sense – especially within the research community – of long established relations of trust. Nevertheless, questions arise about how people understand research, why they participate, and why – in some cases – they do not. Instances where whole communities have declined to participate in trials (A. Leach *et al.* 1999), and where follow-up studies have been unable to re-recruit past participants, highlight a more complex social engagement with researchers than is captured in the simple idea of “trust” and “good relations”. Moreover, public attitudes to science and research in The Gambia cannot be considered in isolation from the wider world that Gambians, now inhabit whether linked to migration, or their burgeoning access to international communication whether through the new telephone networks, radio, satellite TV and internet.

4 Sites and methods

The ethnographic research on which this paper is based was conducted between March and November 2003, and has focused on two contrasting research sites.¹ The first is the rapidly growing town of Sukuta in Western Division and the second has been the rural village of Tambasansang in Upper River Division. The aim in choosing these sites was to cover a spectrum of contemporary livelihoods and experiences in The Gambia. This needs to be understood, however, within the limitations of a stronger focus on Mandinka-speakers, who dominate in both sites, than on members of other ethnic/language groups. Both sites are within the areas covered by on-going and past medical research programmes. The MRC Sukuta Birth Cohort study is researching infant immunity and responses to infection (e.g. by Cyto-megalo Virus, CMV) and routine vaccination. Tambasansang is within the area covered by the large government and MRC Pneumococcal Vaccine Trial (PVT).

In each site, the research consisted principally of detailed narrative interviews taking the form of vaccination and research engagement “biographies”. These traced parents’ unfolding experiences with each child, and took an open ended format that enabled the narrative to follow the issues most important to them. The 50 biographies in each site built on 9 focus group discussions held with each major ward (*kabilo*), that men and women attended, and which covered infant care practices, understandings of vaccination and views of MRC activities. The biographies were complemented by many extended key informant interviews and by participant observation in home, clinic and wider social settings to explore conceptual issues surrounding infant health, and the social dynamics shaping health practices. Interviews were also conducted with community health nurses, midwives, village health workers, traditional birth attendants, and MRC fieldworkers and researchers. We interviewed eight fieldworkers and two field supervisors in Basse, and six fieldworkers in Sukuta – and had informal conversations with four more.

¹ The UK researchers (Leach and Fairhead) were in The Gambia for 10 weeks, and the Gambian researcher (Small) continued for the full period, with two further week-long visits by Leach during this time.

Existing studies of parent's engagement with vaccination and medical research in The Gambia have been based either on questionnaire surveys (Hanlon *et al.* 1985 and A. Leach *et al.* 1999) or on focus group discussions alone (Lovell 1999). These studies, which aim to uncover people's beliefs and attitudes around vaccination and research, have contributed to some of the stereotypes outlined above, and described in greater detail below. In contrast, our biographical and ethnographic approach enables us to consider how people's engagement with vaccination and research unfolds, and how this is linked to broader contexts of infant care and of people's social worlds. This approach also enables us to see what a research intervention, such as a vaccine trial, actually comes to mean to people in the context of their wider experience of health delivery, and their ongoing social relationships.

During this research, we were not able to observe directly either the consent process or the institutional monitoring of this. This clearly places limitations on the ability of the study to describe implementation practices. Rather the focus is on representations of these practices as given in the narratives of fieldworkers and, indeed, of villagers. Because of the focus on the perspectives and engagements of villagers and fieldworkers, in-depth discussions were not held with the senior MRC researchers involved with the studies, although some were consulted at the start of the research to gain their inputs as to pertinent questions for the ethnographic research. In the analysis of research practices and public engagement, it is particularly important to distinguish between research protocol (what is supposed to happen), the procedures put in place to ensure that it does happen, the way these are actually implemented by fieldworkers, how fieldworkers describe this, and how interventions are interpreted by publics. The emphasis in this paper is on the latter two dimensions.

The focus on in-depth research in the communities of two fieldwork sites during a concentrated period has been important to enable parents' perspectives to emerge. However, it also brings certain limitations. First, there are questions of generalisability. In particular, in relation to the PVT there is a risk of over-generalising from the experiences of a single village of a trial which as will become apparent has been ongoing for a number of years over a large area, engaging differently with different communities over this period. Second, the time-bound nature of the study raises questions of comparability. In particular in Basse, by the time of our research recruitment into the trial had ceased, whereas in Sukuta it was ongoing.

5 Ethnographic settings

Sukuta, in Gambia's Western Division, is part of an area of rapidly growing population due to high fertility, limited emigration, and immigration both from up-country Gambia and neighbouring countries. It grew from a Mandinka village in the 1960s of 1,500 inhabitants, to a population now of 13–15,000. It retains its village heart, divided into quarters inhabited by different founding families, but has expanded to incorporate a huge variety of immigrant populations from all over The Gambia and beyond. Migrants have either purchased land, and built high walled compounds, or rent accommodation. In the process the village has transformed from a

rural to urban economy, and has become an economic hub attracting commuters from surrounding villages, with a growing engagement with the coastal tourist trade. The health centre is on the edge of the old village, and is the base for an infant welfare clinic twice a week, and for trekking to outlying rural and peri-urban settlements. MRC has established an office within the health centre compound, as a base for the current birth cohort study.

The other study site, Tambasansang, is a predominantly Mandinka-speaking village in the extreme east of the country, ten kilometres from the town of Basse in Upper River Division. Its closely clustered, fenced compounds in the expanse of savanna suggest a self-contained rural community, but the mobile telephones which hang from the shade trees in many courtyards reveal it – like Sukuta and the rest of The Gambia – to be a multiply-located community, regularly in contact with sons in Europe, North America or elsewhere in Africa who are frequently considered as compound heads and strongly relied upon for their remittances. Although predominantly Mandinka-speaking, many village women have moved to their husbands from two Serrehuli villages. Equally, many village daughters have married out to a Jahanke village. The Basse town clinic currently sends a trekking team to the village monthly for routine mother and child welfare services, including the Infant Welfare Clinic (IWC) that administers vaccinations. This dates only from 2002; previously the village was served by a trekking clinic in the neighbouring village of Damphakunda. Tambasansang is one of 3–4 villages long involved with MRC research from the field station in Basse.

6 Health institutions and their representations of their publics

In this section, we consider how staff in routine vaccination (EPI) and in medical research settings represent the publics that they serve. In particular, we consider how staff differentiate between participants and non-participants in their programmes. Our interest here is not in whether these explanations are “correct”, but in the ways that public engagement is talked about in relation to health workers’ practices, so that we can later explore the contrasts between health workers’ perceptions, and parents’ own reflections on the place of vaccination and research institutions in their lives. We also draw attention to how health workers’ representations reflect the structures and sedimented organisational cultures in which they work, and the imperatives of their jobs. First we consider health workers in routine EPI programmes, and then medical research focusing particularly on fieldworkers, in the two focal case studies.

6.1 The Infant Welfare Clinic

At the routine Infant Welfare Clinic (IWC), a team of Community Health Nurses registers new babies and assign their blue clinic cards, weighs each baby, examines its card to see whether and which vaccinations are due, and administers the vaccinations as appropriate – often rotating these different roles amongst them. In Sukuta, a senior midwife and a public health officer play a supervisory role and sometimes give health talks; in

the Tambasansang trekking clinic, the head of Mother and Child Health (MCH) services plays this role, assisted by the Village Health Worker.

For all these health workers, a key objective is to ensure that mothers complete the schedule of vaccinations on time and to facilitate this, that regular monthly weighing is sustained – at least until a child is eighteen months old, and preferably until he/she is five. Mothers whose practices fail to fit the prescribed schedule, and which thus compromise overall EPI aims, are generally described as “defaulters”. This strong term with its condemning overtones groups a large variety of particular “failures”, including: (a) being late for first vaccinations, ideally given a few days after birth; (b) missing one or more of the Diphtheria, Pertussis and Tetanus (DPT) vaccinations supposed to be given at 2, 3 and 4 months; (c) missing measles vaccination at 9 months; (d) being late for any of these, and (e) showing a gap in weighing records of more than about 2 months.

Whether in policy analysis, research, clinic management or daily clinic practice, there is considerable attention to why different people comply or default, which has led to a range of ways that people are categorised. In both sites, frontline workers describe attendance rates as good, with the defaulters being an exceptional and problematic few.

Health workers tend to represent compliance in two particular ways. First, as an active decision by people who come to “know the importance” of vaccination through education (school, talks etc.), and use only the clinic for treating child illness. This view exemplifies “active demand” as portrayed in wider literature on vaccination (e.g. Nichter 1995). A second view portrays clinic attendance as more a question of “routinised” or “community demand”, something that has become an established part of childcare and of the social round of many women. This view sees attendance at the infant welfare clinic as a social event, where women can dress themselves and their babies in their best clothes and share a cheerful gathering, a break from daily chores, at which other news is exchanged and solidarity among women celebrated and built. Casual observation of an infant welfare clinic in progress would seem to support this image of “African women together”. Indeed international tourists are now bussed from their hotels to see precisely this image in Sukuta.

With this the norm, “defaulters” have come to be imaged as, first, those who travel a lot, and forget to take their children’s health cards with them. Second, those few people who prioritise economic activity (gardening and trade) over health and make no time for clinic, and third, those who neglect clinic visits if their children are well (although when put on the spot, may use travel as an excuse). These reasons for default are at times imaged as a particular ethnic trait (e.g. in Sukuta, travel is often linked to Jolas or others from Guinea Bissau, and over-zealous gardening to Mandinka women). They are also linked to education. Earlier research in Sukuta had explored the reasons for default in the mid 1980s (Hanlon 1985), where the issues raised in questionnaire survey given half to defaulters, and half to compliant parents, dovetailed with health professionals’ concerns. It found that mothers of poorly vaccinated children had (a) a poorer knowledge of the diseases against which their children should be vaccinated; (b) a more superstitious view of disease

causation, and (c) came from larger, less educated and less literate families.² Vaccination uptake did not appear to relate to income, paternal occupation, or size or style of housing. The authors also suggested that the heavier workloads in looking after a large number of children, added to the fact that more non-compliant mothers were petty traders who had to spend a great deal of time in local markets, may have created pressures making it difficult to attend the clinic. The study also indicated that non compliants (defaulters) made fewer routine infant visits to the health centre (but not necessarily fewer visits for child illness).

As will become clear through analysis of parental narratives, these categories do not fully reflect parent's realities. Indeed, they obscure many of the issues that are important to parents and that shape their vaccination practices. In particular, they overlook how everyone is integrating multiple forms of medicine and health support, rather than being either "traditional" or "modern".

6.2 Research: The Pneumococcal Vaccine Trial

In the context of vaccine trials, frontline workers also describe and problematise publics in ways which reflect the imperatives of trial organisation and of their own work.

The PVT is a joint MRC-Gambian Government phase III trial of a vaccine for pneumococcus (the types which causes pneumonia and meningitis) which originally aimed to determine its effect on infant illness and mortality. A positive result in an African context would be a key negotiating point for those pushing to have this vaccine introduced into routine immunisation schedules throughout Africa, despite its relatively high cost. Studies had been conducted in the region for over 10 years in preparation, to document existing illness and mortality, and assess the safety and efficacy of vaccine alternatives. Prior to the trial and at times during its implementation, there was an extensive, and state-of-the-art according to current views of best practice (e.g. Nuffield 2002), information and communications programme which outlined the trial objectives and procedures. This used radio, community music and theatre, sessions with Village Health Workers and village reporters, and community and district meetings drawing together researchers with local and national health authorities, politicians and opinion leaders. This wider communication complemented discussions and information provision to individuals when asked to participate.

The pneumococcal and control vaccines were given to children three times (at 2, 3 and 4 months) integrated into routine government vaccination programmes. MRC workers conducted consent procedures, and helped the government vaccinators who administered the vaccine (half pneumococcal vaccine mixed with DTP/Hib, half just the latter as a control). In the area served by Basse, an MRC nurse and fieldworker attended clinics and outreach sessions, and at the time of our research, were occasionally joined by MRC doctors who helped screen all trial children reporting sick for symptoms of Acute Respiratory Infections.

² Thus only 2 out of 23 poor compliers 'believed in scientific cause of disease'; but 26 out of 42 compliers did. Of all those surveyed, 28 of 65 thus had this "belief" (identified if responses favoured contamination of food, dirtiness, nutrition, feeding practices and poor child care vs. evil spirits or fate) (Hanlon 1985).

Suspected pneumonia cases were referred for further investigation and treatment by MRC staff based at Basse health centre or Bansang hospital. In other areas covered by the trial, MRC did not have the capacity to place nurses or doctors to treat children at clinic sessions. However it was policy to refer any seriously ill person, child or adult, whether or not in the trial, for treatment at Basse or Bansang, transporting them there by whatever means available, whether MRC or government vehicles. MRC monitored children for 30 months, tracking illness and mortality, and visiting each child at home every three months. The trial recruited existing Village Health Workers and employed further assistants in villages to track births, encourage clinic attendance, and report deaths, paying a small fee for each event recorded.

The trial is managed by a Principal Investigator, a project manager, and a small team of senior doctors, backed up by the visits of consultants such as specialist statisticians, and the punctual oversight of an international steering committee, and a data and safety monitoring board. Everyday aspects of the trial are managed by two field coordinators under their supervision and with regular interaction with these senior staff. They oversee the daily activities of a team of field workers, variously involved in consent procedures, administering vaccines, and surveillance.

When originally envisaged, the PVT needed to recruit around 50,000 children, and for this would have had to cover a third of the country's population (half the area), and to have high levels of consent. For a number of reasons, at the International Steering Committee meeting of January 2002, the primary trial objective was changed to the determination of vaccine efficacy in preventing radiologically-diagnosed pneumonia, and the sample size was reduced to approximately 17,000 children. The protocol was revised to reflect these changes and re-submitted to the ethics committees concerned, which approved the changes. Recruitment to the trial began slowly, not least while changes to the protocol were being negotiated internationally. The PVT scaled up in the first 4 months of 2002 from four clinics, to all 15 clinics in Upper River and Central River Divisions, but was then scaled down again to the 9 more accessible clinics once it became clear that the numbers of children being enrolled in these could use up all the trial vaccine before its expiry date.

Built into the original trial sample size was an assumption that about 8 per cent of mothers would refuse, a further 5 per cent would not complete the necessary three vaccinations, and an added 10 per cent contingency. This – perhaps unrealistically – high participation rate proved to be unnecessary to enrol the required number of infants, however, given the reduced scale of the study and higher than anticipated birth rates in the study areas. While the pressure was off achieving the very high participation rates originally anticipated, then, substantial participation rates were still important. Higher participation made the research more cost-efficient as it could be focused on fewer clinics, and pockets of low participation could be seen as potentially problematic, for reasons of trial efficiency, sustainability and broader public relations.

In this context, fieldworkers and their supervisors, in representing their work to outsiders such as ourselves, place great emphasis on communicating the objectives of the trial, establishing participation, and

addressing “refusal” which is seen as a problem. This is not simply linked to the trial imperatives, but also to routinised practices within Gambian health and research services. Many of the MRC fieldworkers have earlier worked in the health service, and have been involved in routine vaccination. They are used to considering parents who do not adhere to routine vaccination as “defaulters”, and to addressing this problem. Fieldworkers forward assorted analyses to account for trial acceptance and refusal.

At its most blunt, refusal is attributed to ignorance (deficit of knowledge). As a field supervisor put it:

We gauge people’s understanding from the acceptance rate. If it is high, we assume that people have got our message. If they refuse, we assume misunderstanding, and sensitise them.

(Interview, Basse, 17 April 2003)

Here acceptance or refusal has become a proxy for people’s comprehension of the trial. The question is ‘why people refuse’, and not ‘why people consent’. Consent is expected. The underlying assumption for fieldworkers is that consenting is the right thing to do. That consent is expected is revealed in the way fieldworkers in the Gambia speak about it, saying ‘we consent them’, rather than speaking of people giving their consent (a passive phraseology that is echoed around blood collection, saying ‘we bleed them’, not that ‘they give blood’).

Nevertheless refusal is at times construed as active but misguided rejection. Whilst MRC claim to have ‘excellent relationships with the community’, they have at times been faced by whole villages, or at least large sections of them, who refuse study participation en bloc (e.g. A. Leach *et al.* 1999). MRC generally pass over such villages when planning trials, which can give a false impression of wider acceptance rates. In the PVT, such exclusions were not made. At times, though, significant sections of certain villages did decline participation in apparently more orchestrated ways. The nascent town of Gambisara and some villages within its district became a well-known case in point, with district enrolment never exceeding 57 per cent (Cutts, pers. comm.).

The different explanations for refusal draw on and reproduce a particular kind of social categorisation.³ First, fieldworkers at times ascribe refusal to ethnicity, with the Serrehuli people being singled out in this respect. They also ascribe refusal to being “traditional”, leaving ambiguous whether by tradition is meant a greater respect for Islamic authority, health practices less shaped by biomedicine, or disengagement with the state administrative structures. In potential contradiction, others ascribe refusal to “travel” – with refusing villages understood to be those with greater diasporic connections in Banjul and internationally, bringing external distortions to benign local sentiments. Such explanations are not unique to fieldworkers, and are also current among senior health policymakers. Beyond these more general categorisations, fieldworkers have identified political differences within communities to explain “refusal”. In one village, they attributed it to a

³ Data here are drawn from anonymised interviews with PVT fieldworkers conducted in Basse, May 2003.

longstanding political division between supporters of government and opposition, into which MRC acceptance was drawn. In other cases, they attribute refusal to certain communities that are new to MRC trials: as they fail to understand the benefits that MRC can bring, they have nothing to offset negative rumours about MRC. Indeed some fieldworkers spoke of a decline in refusal rates in certain villages as the trial progressed, as those asked to enrol later had had the chance to observe those enrolled earlier receiving free MRC treatment.⁴ In another they identified particular people whose personal grievances with MRC or the health service led to the spreading of malicious and false information. In another, they attributed refusal to the amplification of individual “bad experiences” with MRC – e.g. in having a family member whose death was attributed to MRC care. In some contrast, one “refusing” village was construed as “wealthy”, so less in need of the perceived free treatment that encourages people to accept elsewhere – an issue considered below. Other communities are constructed as ‘too poor to refuse’; an epithet applied by fieldworkers for example to small Fula hamlets.

The trial administration responded to refusal by large sections of communities both by conducting inquiries and by investing in more intensive sensitisation efforts. As part of their in-service training programme, for example, fieldworkers were sent to several such communities to conduct case studies into the reasons for refusal. Where and when it became necessary, additional community sensitisation meetings were held, with particular efforts made to invite local and national political, religious and cultural figures into these.

Fieldworkers assume much of the day-to-day responsibility for people’s engagements with the trial. As fieldworkers make clear in their narratives, not having refusals, or gaining acceptances in villages which had become stereotyped as problematic, became a point of pride. In their own views, although not in the view of their managers, several became renowned for “turning around” problematic, refusing villages. One fieldworker, for example, described how following his success in one Serrehuli settlement, he was transferred to another as a “troubleshooter”. The trial’s more senior managers indicate that transfers were actually made for other reasons. Yet the self-perception among fieldworkers reveals their own rather different reading of professional and institutional logic, and of what it is to do good work.

There are several ways in which fieldworkers see themselves as able to improve participation, beyond the PVT’s wider communication strategies. First, several described how they built strong social links with so-called opinion-formers – those who might be expected to have influence or leverage over the community. Who this was varied greatly, and fieldworker skills and tactics partly lay in finding out who might provide useful links to different sections of communities- perhaps the Imam, perhaps a Traditional Birth Attendant, or certain elders, traders or others. Investing in and supporting the Village Health Worker – a role within the government’s Primary Health Care strategy, usually filled by a local volunteer with some paid a stipend by the

⁴ These opinions are somewhat contradicted by district-level evidence that the participation rate in the PVT was fairly constant in each year of enrolment: for example for Basse it was 73 per cent in 2001 and 80 per cent in 2002; for Fatoto it was 88 per cent in 2001 and 84 per cent in 2002 (Felicity Cutts, pers. comm.)

community – could be a useful strategy where the Village Health Worker was active and respected (by no means always the case).

Second, fieldworkers understand villagers to be motivated to participate in the trial due to the privileged and free treatment that it offers to study subjects. This is disputed by the trial's senior managers, who emphasise that MRC had no such policy and lacked the resources for this, although tried to help anyone with serious illness, irrespective of whether they were in the trial. However, the statements of six out of the eight fieldworkers we interviewed suggest an association between trial participation and free treatment. Thus as one put it:

We explain that in PVT there are 40,000 children so there are not the resources for everyone. We cannot treat the whole family, only immediate family, the mother and siblings, but if the father goes with the PVT card he will be assisted.

Another said: 'What they want is the free treatment. This is clarified during the time of recruitment'. And another said: 'We explain that they will get treatment for as long as the programme runs. In reality, although the treatment ends with the programme, MRC staff often do go on treating to avoid a feeling of ill-will and hence refusals in later studies'.

It is possible that for longer-serving MRC fieldworkers, these statements reflect confusion with earlier phase I and II trials and other studies which had offered free treatment to study subjects. Indeed, the first fieldworker quoted above had worked with an MRC malaria trial in the Basse area that had given such treatment, while another, in the same position, said of the PVT: 'The problem with this trial is with the treatment – some villagers complain that since the end of the malaria trial, it has been phased out, so they are no longer getting it. I am not sure if this is true'.

While the fieldworkers who made these statements are not doctors and would not normally have been administering any treatment, and while the PVT protocol and information sheets used in the consent process make no mention of any free treatment, it seems clear from their narratives (and indeed from the perceptions of villagers that we explore later) that issues of free treatment became part of the communication processes around the trial.

Third, fieldworkers are in a position to select strategically which aspects of the trial to explain or emphasise. The most critical moment for this is at a baby's first clinic registration soon after birth, when the fieldworker is supposed to explain what the vaccine trial involves, while giving the mother the one-page written explanation and consent form. Fieldworkers have a public discourse that, in line with their training, they explain the trial procedures in full, including the placebo – that the trial is a form of research, in which those vaccinated have to be compared with those not vaccinated to see if the vaccine is effective. In formal interviews, all fieldworkers emphasised this. However, several discussed the difficulties of getting these issues across given villagers' own concepts surrounding injections, vaccinations and so on. For example, as one put

it: 'We take pains to explain that it is a trial. We think the vaccine may protect the child from pneumonia and meningitis, not that it will protect. Most parents know that immunisations protect rather than are a cure, but others consider it a treatment' – a specific conceptual issue which we deal with below. In informal conversation, one fieldworker volunteered how impossible it was to convey the idea of placebo, and how he dealt with this. He said: 'In reality only half will get the vaccine, but we don't explain it that way. We explain that they will definitely get the pneumococcal vaccine, otherwise they might think it was a trick' (informal conversation, 16 April 2003). As we did not observe the consenting process, we cannot comment on whether fieldworkers actually bend formal modes of explanation in practice, and senior PVT managers strongly deny that this happens. Certainly there are many communications efforts and management, training, procedures and monitoring in place to ensure correct information concerning this particular aspect of trial procedure. However, it remains a difficult issue to get across, and one which as later sections will show, is largely not apprehended by villagers.

6.3 Research: The Sukuta Birth Cohort Study

In the Sukuta study, too, institutional structures combined with the imperatives of the investigation to generate particular concerns with acceptance, and vocabularies to describe and account for participation and non-participation. The study aims to understand how the immune system deals with early infections, and the legacy of infection on subsequent immunity. It is tracking immune response to three early life infections that give no symptoms in small children: placental malaria, Cytomegalovirus (CMV) and Epstein Barr virus (EBV). To do this, the study needed to recruit several hundred babies into the trial at birth, and then follow them monthly for the first year, and then at 3 monthly intervals for subsequent years. The study involved placental blood and urine sampling at birth, blood sampling from the mother at 6 months, and from the baby once a viral infection was found (or at 4 months, in the case of infection during pregnancy).

The logistics required the research to operate from a single health centre. Statistical requirements of the study required that a high proportion of babies born at the health centre were recruited into the study. Because placental blood samples needed to be analysed immediately, only babies born in the health centre between 2am and 4pm on weekdays could be recruited, adding further to this imperative. To maintain sample size and the cohort structure, the study needed not only to recruit participants but also to retain those recruited.

Given the single location of the study, prior communication about it took place on a much smaller scale than in the PVT. The study team held initial meetings with community leaders, but relied more heavily on informal communication about the trial within the well-respected health centre where they were based, and on the individual consent process. Later in the study, to stave off what the study team saw as emergent public misunderstandings and to consolidate community support for the study, a programme of community outreach was planned, including a public meeting at the health centre.

A team of MRC fieldworkers is responsible for the consent process, home visits, sample collection and monitoring. They give a brief explanation while the mother is in labour, and take samples needed at birth that will be used only if consent is given. After delivery, they explain the study more fully to the mother (and father if present), verbally translating an information sheet. A woman might sign the form at once, or if she awaits consultation with her husband, he must be present in time for the sample to be sent to the laboratory. A follow up visit is made to the mother's compound to take urine samples, and this is used to ensure that consent is still available.

The study is socially sensitive for several reasons. First, it involves asymptomatic infections and thus the study is not obviously preventative or curative in an immediate sense. Second, given widespread publicity for HIV, people tend to associate “viruses” and being “sero-positive” with HIV, and thus there is a problem of associated stigmatisation. Third, the study involves blood taking from mothers and babies.

In these circumstances, fieldworkers feel that consent and continued participation hinges heavily on their explanations and social engagement. The fieldworkers are highly sympathetic to mothers' concerns and show a clear commitment to children, and enjoyment in interacting with them. They have also developed creative ways to explain the trial, and to convey more difficult or problematic concepts. These include explaining the immune system as “the body's soldiers” (*baro djato la soldaro* in Mandinka). They also use analogies to explain that there are many different sorts of virus (not just HIV): ‘The virus is just like an umbrella – there are many kinds, just as the Gambia is an umbrella for many kinds of Gambians, Wolof, Fula and so on’.

Despite these practices, some people have declined to participate or have dropped out during the study. Fieldworkers attribute this to several issues. Some attribute refusal to wealth; to ‘those who can finance their medical care and do not need the MRC benefits’. Fieldworkers draw on the idea of private “family doctors” used by such people, who both provide an alternative to MRC and government health care, and are said sometimes to advise against study participation.

Fieldworkers also understand refusal as misplaced worry, whether by a woman herself, by her husband or by authorities in her compound. These worries include concern that MRC takes, steals or sells blood, which will deplete a non-replenishable life force. Those who decline are, in these terms, those who have not yet understood the scientific reasons for blood samples, or the small amounts taken and lack of harm they cause. Conversations around this fade into discussion of wider problems of blood donation, and the reticence of many Gambians to do this even for close family members due to the harm it is believed to cause to the donor. Worries also encompass the idea that MRC is promoting family planning, of particular concern to some husbands; or that MRC practices include inappropriate nude examinations. Fieldworkers attribute some of these concerns to particular ethnic groups: for instance they claim that Fulas have been particularly difficult to recruit into this study, as they harbour particularly strong concerns about blood-taking.

7 Vaccination in the process of raising an infant

These categories – of good vaccination complier and defaulter, and trial acceptor and refuser – and explanations for them, are rooted in the institutional needs of health and research institutions, and in established modes of discussion amongst health workers, as developed through the long history of these institutions. However as we turn to parents' perspectives, we find that these categories obscure the range of experiences, concerns and dilemmas faced by parents as they seek to raise their infants and keep them healthy amidst a range of health care providers.

Giving birth to and raising an infant is considered by villagers as fraught with hazards. They orientate many practices and forms of expertise and specialism towards either reducing or mitigating specific risks, or ensuring that an infant has the strength (*sembo*) or bodily protection (*balakanta rango*)⁵ to withstand uncertain or unpredictable events. Parents understand each child's particular history and health status as unique, depending on its own path through unfolding events, hazards and circumstances; a particular history that can influence how parents think about vaccination for that child, or indeed participation in medical research.

People consider these hazards to begin at the foetal stage, from the time that a woman is recognisably pregnant (*harijeta*), and the foetus has progressed beyond the stage of being just the man's semen (*maneo*) to becoming "thick blood" (*yelo kunturo*) at about 2 months, and a frog or lizard-shaped clot at 3–4 months. They consider that the foetus's growth and development can be damaged not only if a mother is ill, but by *jina* (*djinn* spirits), making it inadvisable for a pregnant woman to go out in early afternoon or at dusk, when these are thought to roam freely in the winds. Sexual intercourse is thought to be beneficial, however, at least before 7 months when a woman becomes too tired and heavy, as it facilitates delivery and gives the baby strength, with some considering male fluid actually to add substance to the foetus.

The period immediately after birth, these days facilitated by one of the village's three trained Traditional Birth Attendants, is considered as one of particular vulnerability. Many parents tie a piece of cloth around a newborn's wrist as a sign that it is part of the human world; otherwise a *jina* might come and tie its own cloth, to claim it as one of its own. Some consider that before the eighth day, when the baby is publicly named and recognised as a human being, it should not be brought out of the house except for special washes over the spot where the placenta is buried in the front yard. This practice is strongly adhered to in Tambasansang, where despite the government policy that babies should have their first clinic registration and BCG vaccination immediately after birth, women do not attend until after this eight day period, even if this means missing the trekking clinic's monthly visit. In Sukuta, women appear to be less concerned by this, and many do now venture out when their babies are only a few days old.

⁵ Local language terms given are in Mandinka. The majority of our interviews have been with Mandinka-speakers, and the concepts and practices described thus apply only with certainty to Mandinka speakers, rather than those of other ethnic/language groups.

People consider that neonatal deaths, and repeated neonatal deaths, can simply be the will of Allah, or they can be due to a jina or in Islamic perspective, “devil” or setano in you that “does not like children”. If they suspect themselves of having this problem, women might go to a marabout for a special talisman (safe), a piece of Arabic script sewn into a small leather pouch, this one worn on her head, to protect her future babies.

Many parents also place a variety of talismen or safe (“jujus”) on their babies, for balakanta rango (protection). It is often a baby’s father who provides these, as part of accepted gender roles in parenting. Some are worn around the waist, others the neck, wrist or ankle. Different marabouts prepare slightly different styles. The main function of these talismen appears to be protection from moo jawolu (bad people) and buwallu (“witchcraft”), but they are also felt to give protection in a more generalised sense, from hazards that one cannot know. Those who claim not to “believe” in talismen frequently put them on anyway, perhaps due to kin or peer pressure, a husband’s pressure, or simply “just in case”.

With the nourishment of breastmilk, people consider that a baby grows and accretes strength (sembo) through a series of stages: from a scrunched up newborn to a baby that can stretch out; through a punctual moment of “putting on flesh” (balo subuduno) at 2–3 months which “opens up” the body to receive and benefit from more milk, and initiate subsequent steady, gradual growth. They observe that the baby will often be restless and feverish at this time, and a first-time mother might be worried, but if she consults an elder, they will reassure her that ‘oh, it is just more flesh coming’. The later stage when a baby can hold its back and head up (“neck straight”, kantilindo) signifies the stage at which it can be carried on its mother’s back, and also the moment when a woman might be considered available again for sexual activity (see also Bledsoe 2002). This is a negotiated length of time, because while husbands might press for it earlier, women are strongly concerned about possible damage to their baby’s health by resuming sex too early. Some – from a koranic perspective – insist on abstinence for a minimum of forty days after birth. If a mother has sexual intercourse while breastfeeding, some consider that the man’s sperm enters the milk and can lead to diarrhoea and malnourishment. The baby will lose strength (sembo doya). People consider the seriousness of the effects to depend on the age and strength of the baby, its gender (they can be worse for boys than girls) and whether or not a protective talisman is in place, but generally, ‘a baby of a good weight is an indication that one has abstained’ (Interview, elderly woman, Tambasansang, 5 May 2003).

If a mother falls pregnant again while her baby is still breastfeeding, people consider that the state of timparo results, causing the breastfeeding child to become sick, weak and thin, sometimes with vomiting and diarrhoea. Some interpret this as simply due to the double load of a mother attempting to nourish two children at once; others, to fluids from the developing foetus, including residual semen, entering the breastmilk. Avoiding timparo is one of the reasons why women are so interested in birth spacing (and some use contraceptives to this end – see Bledsoe 2002); if it should occur, there are local herbalists who offer treatment.

People suggest that a large variety of illnesses (kuran) can set back an infant's growth and development. Within a complex set of causal fields, these are variously attributed to physical happenings (e.g. falls, exposure to bad wind or damp, sometimes linked to the entering of a disease seed – kuran keso – into the body), to the agency of jina or “bad people”, to events which disrupt socio-ecological orders (e.g. a frog eating faeces left in a courtyard), or to Allah. The start of the rainy season is particularly associated with illnesses manifesting as diarrhoea and as fever – many of which are glossed as “malaria”. The causal fields for different childhood illnesses can interact, while the state of being ill (kuranta) can be both hastened by, and further encourage, weakness (sembo doya) caused by other problems such as those with breastfeeding.

Maintaining health, for an infant as for an adult, is also thought to require maintenance of the quality, quantity and flow of two sorts of fluid in the body: blood (yelo) and “water” (jiyo), which originates in the head, and links with the kidneys and with male and female reproductive fluids. Each sort of fluid has its own set of routes around the body in distinct vessels (faso). People consider that if blood and fluid stop moving, the body will become very hot and sickly. If the quantity of blood lessens (yelo doya), the body loses strength, and becomes weak, with headaches and dizziness. This is both life-threatening in itself, and renders the body more vulnerable to other problems such as those of disease (kuran). This importance of overall blood quantity to health and wellbeing shapes a field of enormous worry about giving blood, whether in blood samples or in transfusions. This applies to babies and children in much the same way as to adults: taking blood from babies does not seem to be more problematic because they have less of it overall; rather, what is critical is blood quantity in relation to bodily size and activity, and it is for this reason that some say it is more problematic for a woman to donate blood in transfusion than a man, since she has a higher workload. Nevertheless, certain foods are thought to build blood and give it strength, including fresh groundnuts and cows' milk, while villagers name 2–3 leaves that can help replenish blood if it has lessened, complementing the medicine (boro) which hospital doctors and MRC fieldworkers also give out for this purpose after taking blood samples. Problems with blood quality can also affect wellbeing. In particular, fonyo is a term for a set of ailments, frequently claimed to be brought by wind, which people describe as causing the blood to turn “black”; associated symptoms range from boils to insatiable itching.

Practices in seeking therapy for these various ailments range from visiting local herbalists, predominantly male and female elders in the village or its surroundings known for their experience in treating particular conditions; to seeking the help of a local marabout, to seeking advice and medicine from the Village Health Worker (in Tambasansang) or from one of the nurses at the monthly trekking clinic (Tambasansang) or main clinics in Sukuta or Basse. For most ailments, the sort and sequence of treatment sought depends on how the particular course of illness interacts with practical issues such as the availability of transport, drugs and money to pay for them. These issues in turn are shaped by intra-household and gender negotiations, with mothers assuming primary responsibility for minor therapy-seeking, but often attempting to call on a father's resources to pay for transport or more major hospital treatment. However, in contrast with this flexible field of therapy-

seeking are certain illness categories which require particular therapeutic forms. In particular, many villagers and certain herbalists claim that fonyo – black blood – should never be treated with western medicine. In particular, it is incompatible with injections, widely regarded as the most effective form of hospital-based treatment. Fonyo and injections do not agree (penko anin fonyo ma ben). Several villagers can relate experiences where a child with this ailment was treated by injections – in one case, more than 20, in the MRC ward of Bansang hospital – with disastrous consequences. In reasoning about this incompatibility, one elderly woman explained that fonyo and injections are both poisono (a term derived from the English poison but without negative qualities; rather, it connotes a strong, powerful substance that goes directly into the blood). Such very different forms of poisono should not meet (Interview, 5 May 2003).

Routine vaccinations are now an integral part of this set of practices for promoting and maintaining infant health. While there is great variation in the extent to which women associate particular vaccinations with particular diseases, vaccinations in general seem to have been assimilated within the broader field of concepts and practices which promote and protect infant health. Women attach particular importance to what they term the “3 month injections” (karo saba penko), those given at 2, 3 and 4 months for DPT and Hib. These are given at bala subunduno time – complementing and boosting this phase of growth. The fever and crying associated with bala subunduno and as a vaccination reaction are interpreted in the same way – as evidence of effectiveness. A vaccination, like any other injection, is interpreted as a powerful poisono which goes directly into the blood, where it plays multiple roles. It is seen to have a general role in giving the baby strength (sembo). It ensures that all the illness that is, or may be, inside a baby’s body disappears. And it gives protection against further illnesses.

For instance, one mother in Tambasansang (TM017)⁶ felt that vaccination was a particular priority for children whose first few months of life fall in the rainy season, as ‘childhood diseases are many then’, while infants are more often left in potentially unhealthy conditions either with their mothers in the fields, or with weak elderly people in the village. This suggests an understanding of vaccination as having an immediate effect, being important for child health at that moment, rather than a futuristic protective one.

In their protective role, mothers say that talismen and injections complement each other as means of child protection: “a be ka ta nyoo la” – they both go together. Just as talismen give protection, so a baby’s injections at the clinic give protection – the same phrase is used (a di tankanding rano). One group of women in Sukuta explained how both protect a child against bad people (mo jawo) and bad wind (fonyo jawo). In other words, people appear not to maintain separate categories of disease causation associated with different forms of appropriate protection. Moreover, they emphasise that life is uncertain; you don’t know what will happen or bring a problem to your child, and both these forms offer generalised protection.

⁶ Reference codes are to narrative interviews recorded from parents in Tambasansang (TM) and Sukuta (SM).

The distinction between vaccinations as preventative and other medicines as curative may thus not reflect people's experiences and conceptual worlds. There have been many critiques in anthropology of the idea of "perfect health"/"cure". It may be more appropriate to see injections (penko), covering both those given routinely to infants or taken when a problem strikes, as helping strengthen the body to cope with or stave off illness. As Samuelsen notes in Burkina Faso, villagers (and in this case a local healer practising a local scarification technique) use the term "vaccination" for both preventive and curative incisions, in contrast with health care personnel who distinguish clearly between injections as vaccine and injections for treatments (Samuelsen 2001: 170). Once immunised, many Gambian mothers recount that it is not that a child will not get a particular illness, but that he or she will get it in a milder form (e.g. the case for measles); in other words, he or she will be better strengthened to deal with it.

The Mandinka notion that injections given in infancy strengthen a child in a general sense (rather than preventing particular illnesses) does not square with the views of health care personnel and most scientists, for whom particular vaccines protect against particular diseases. However, it might be seen to correspond with strands of scientific debate emphasising the non-specific effects of childhood vaccines, and the limits to specific effects (Aaby 1995).

Mothers are strongly aware of the fever and swelling which occur as side-effects of routine vaccinations, although during the research to date no-one has spoken to us of more serious adverse events. Many mothers find vaccination-related fevers tiresome to cope with, especially in babies who are fractious anyway, or who must be walked long distances in the sun after vaccination because the clinic is far from home. However, most women understand such side-effects as an indication that the vaccination is strong and effective. As one Sukuta mother (SM001) put it: 'my babies experienced swollen arms, which I would massage with shea butter and mentholatum, and fever, for which I would use he would use paracetamol or leaves. At times I was tempted to stay away on clinic day for fear of high fever or swollen injection site, but my husband would say that it is the strength of the injection'. "Modern" injections are seen to be stronger. This was the conclusion reached by SM001 whose 7th child in the late 1980s suffered far more serious fever than earlier children, after discussing with her husband and other women (at first she thought it was because this 7th child was female, whereas her previous children were boys). However women sometimes attribute particularly serious fever and swelling to the nurse having a "painful hand" or not injecting properly. A nurse with a "cold hand", in contrast, is thought to lead to less pain or fever.

8 Ambiguities of the clinic as a public gathering

While attending the infant welfare clinic can be a social gathering, the stereotype of "happy African women" obscures a range of worries and forms of competition and exclusion that also surround clinic attendance; issues which affect different women in different ways.

The infant welfare clinic is a setting for very public display, where mothers and their children are “on show” to others, and open to their scrutiny. For some, this can be very positive, with the clinic as a place to show pride in one’s baby. Thus a young mother from one of Sukuta’s new settlements (SM016) related how: ‘I would find something suitable for my baby, I would also dress beautifully, put on matching shoes, take my bag and go to the clinic. As an adolescent, I loved to draw attention, and I did it’. This mother described how she fed her baby what she thought was egg powder: ‘I wanted my baby to be fat so I could bluff the more.’ Another (SM001) decided always to be punctual because she had been praised in front of the crowded clinic, on one occasion even winning a prize for good attendance, and would not like to be disgraced in front of the same crowd.

However, public display of infant health (or ill-health) is also a matter for status negotiations amongst women. Good health indicates being a good mother who is able to overcome problems, or who has good moral conduct. Thus having a fat baby is proof that one has not had sexual intercourse while breastfeeding, whereas a thin one opens a mother to moral condemnation as having engaged in such improper reproductive behaviour. The backgrounds of certain women make them particularly concerned about how others will judge their childrearing. Thus a mother from the *jeli* (griot) caste in Tambasansang described how:

... even within the griot community there is a “class” type of attitude where some will be superior while others will be interested to see or know how being a griot has improved or worsened one’s livelihood. This is not only visible by the number of assets one has but by the way one cares for the children. Therefore if the child is healthy and beautiful she is admired (TM0019).

In another case, a sex worker, despite living in Sukuta, preferred to attend the IWC in Serrekunda where she had delivered, and where she was not known. As a sex worker she wanted to distance herself from nurses and other mothers who would know her background, and, she feared, would stigmatise her (SM006).

Others find that the particular characteristics and health status of their baby opens them to problematic attention. For example one mother in Sukuta had an infant who refused to be weighed (SM004b); she described how: ‘attempts were made to take him but his crying and disturbances worried me and people would comment on it so I stopped. For people to talk on a person regularly is not a good thing; this can affect the child’. A mother in Tambasansang (TM008) had a very small second baby (1.7 kg). Neither she nor her husband could find any reason for this as the baby was full term. She refused to go to the clinic because the baby attracted so much attention when she undressed it, and was only persuaded to resume by a sympathetic health worker:

I was visited at home by the nurse who advised me to take the child to the clinic, I then summoned the courage to be going. When I went and I undressed her, comments started raining; I was embarrassed I

went back to the health worker and told him of my encounter. He reassured me and gave me courage to be attending regularly. But by this time my baby's weight had increased.

This suggests that the “group camaraderie” and public display aspects of routine clinic attendance, while positive and attractive for some, are viewed negatively by others: by those who feel socially excluded, and by those who fear unwanted attention on themselves or their baby.

The clinic is also feared as a place where children might be harmed by “bad people” with esoteric means (moo jawo), or by “witches”. To protect them from such hazards, many people – including those who do not normally use them – will put a talisman on their baby especially to go to the clinic. The clinic is a crowded place, like certain others such as markets, where one does not know who might be there, and who might have malevolent intentions towards one's child. One mother in Sukuta described how she always avoided taking her child to crowded places, and would take her to the clinic only with extreme worry. As she put it: ‘When a child undresses, especially if the child is healthy and beautiful, all eyes will be on her, and this I fear when the clinic is crowded . . . there are many witches around’ (SM003).

Many mothers see weighing as presenting particular hazards. Certain women have particular talismen which cause their babies to leave behind a trace on the scales which can cause kriss (convulsions). If you are not someone with the same talisman yourself, you need to have a general protective one that will counteract this. Occasionally, when a woman who is feared in this way has just weighed her baby, others will not come forward to follow her in the queue, and this can make the nurse impatient. Thus as one older Sukuta mother described:

I observed that at the clinic, each ethnic group has its protection and there are instances where women are scared to put their children after a Fula woman has weighed her child. The Fulas have a special *binoo* (horn) for an illness that is transmittable from one child to another. It is even worse when the child passes urine on the scale or when one steps on the mother's footsteps . . . an observant mother will never allow her baby to be put on the scale after a Fula woman's baby, she will allow others to go ahead. If the women in the queue also observed that it was a Fula child, none will come forward. The nurse would shout ‘next, next’ . . . they would pretend not to hear (SM001).

These fears also play into ethnic stereotyping, with danger sometimes associated with particular ethnic groups or “foreigners”. Different ethnic groups are seen to have different forms of protective amulet, so that forms of child protection become ethnic identifiers. They are also markers of who is safe or dangerous to be with in the clinic setting, as one can only be sure of safety amongst those who have the same talisman as oneself. In this context, solidarity amongst groups of women at the clinic is as much for security – to keep within a safe group of similar and known people, and to look out for each other – as it is for enjoyment and practical mutual help. In Sukuta for instance, mothers from a particular part of Sukuta town and two outlying villages

have deliberately grouped to dominate the Tuesday clinic session, and with this solidarity, do not necessarily worry about putting on a talisman (SM003a).

9 Time, logistics, and interactions with clinic staff

There are many circumstances and life events that can cause a mother to miss a clinic session, or several sessions, around the time that vaccinations are due. First, this can happen due to extreme family misfortune (e.g. TM020 had an older child die). Second, it can be due to temporary pressure of work. For instance a mother in Tambasansang (TM021) missed several sessions with her third baby as she was temporarily responsible for all the family cooking, as her co-wives had travelled. her co-wives had travelled. A mother in Sukuta (SM002) was a regular attender with her first baby but by the time she had her second, her husband had become a military officer and she had much work in preparing his uniforms and food, and either missed sessions or asked someone else to take the baby. In Sukuta especially, women's work in gardening and trade occasionally compromises their clinic attendance despite their best intentions. Thus Sukuta's gardeners try to re-organise their schedules to enable clinic attendance, by going to the garden in the evening before a clinic day, but are occasionally unable to. A literate businesswoman (SM004) found it hard to find time to attend, and usually managed by going to clinic early to avoid the queues and leaving early. But sometimes these pressures meant she failed to attend. Her narrative illustrates how growing economic autonomy and "empowerment" for women can be associated with pressures which make clinic attendance a greater struggle:

Women's problems are numerous and now there is the issue of "empowerment", whereby women are trying to make ends meet – therefore we women must prioritise. When my child is sick and I have urgent things to do, I either go to the clinic very early and be among the first patients or ask my mother to take the child (SM004).

Third, occasional failures can be due to travel. SM014 had irregular attendance for all three children as she used often to visit her brother, a health worker in Senegal. In Tambasansang, a businesswoman sometimes travelled to Banjul with her baby, but on several occasions left his IWC card behind so she could not attend the IWC there.

Fourth, failures to attend on a particular clinic occasion also reflect practical difficulties in getting to the clinic. One mother in Sukuta had had three sets of twins, and occasionally could not take both as a helper was not available (SM013). In Tambasansang, practical difficulties turn on the struggle to walk to the clinic several miles away in the village of Damphakunda (until an outreach clinic commenced in Tambasansang itself in late 2002): the journey may be impossible for mothers who are sick themselves, have a sick child, have no-one with whom to leave siblings on a particular day, and when these circumstances coincide with the hot season or heavy rains.

Such occasional non-attendances can be compounded both by clinic logistics, and by problematic interactions with health staff at clinics. Thus one woman in Tambasansang went to visit her mother's village, taking her IWC card, but when she arrived she found she had missed the clinic in her mother's village and on returning to her village she had missed the clinic day too. The following month, it rained heavily and the outreach team failed to visit the village. Attendance is more difficult for those whose "3 month injections" coincide with the rainy season. Women in Tambasansang with irregular clinic records recall days when they would go to Damphakunda and find that the nurses had not turned up. This would be especially common during the rains, when nurses would complain that the roads are inaccessible. Nurses also claim never to go on trek on the 5th Monday in a month, during months when that occurs. Such problems of clinic access and supply appear to be relatively common throughout the Gambia, as indicated, for instance, by Lovell's (1999) focus group study.

Women also complain of ill-treatment and rudeness from health workers when they are late or miss an IWC session – something which again was found by Lovell (1999). Our narratives suggest that this sometimes drives them away, and reduces their attendance further. Thus an older mother in Sukuta described how:

Nurses would embarrass people in front of a crowded clinic. If they fail to take their injections, the nurses would be angry with them. Their clinic cards are sometimes placed at the bottom as a sign of punishment. Some who feared being embarrassed and have defaulted, stayed away and would instead send their children to clinic only when very ill. Others will take their children to the outpatients (SM001).

In Tambasansang, several women had a gap in clinic attendance around the middle of 2002. This was attributed to problematic interactions between women and the nurses over lateness:

Due to the distance from Chamoi village to Dampha Kunda some women came in late and the health worker who was not pleased disclosed his anger on them and they were sent away. So when another group of women came from Tambasansang the same health worker was not pleased too and even when we told him that it was far and no means of transportation was available, he would not listen to us. He used abusive words to which we retaliated. Then we were denied treatment and were driven away.

This conflict eventually resulted in women from Tambasansang, encouraged by their Village Health worker, boycotting the Damphakunda clinic and insisting – successfully – that a new trekking post be opened in Tambasansang itself.

When women do miss clinic sessions, they often worry greatly that a backlog of vaccinations will have "stacked up". Too many injections in one go is seen as highly problematic. As one mother in Sukuta put it: 'Vaccinations are good but not when they are accumulated and given at a go. It makes the child sick. I have seen my co-wife's child get ill because she defaulted and when she took the child, three injections were given

at a spot' (SM013). Fear of being forced to have catch-up injections, given the power relations of the clinic in which the nurse tends always to "have her way", sometimes means that women keep their babies away for further months(s), compounding non-attendance. Yet others worry that vaccinations will stack up even further. The story of a businesswoman in Sukuta illustrates how these dilemmas can arise:

I delivered on the 4.12.01 and had a naming ceremony on the eighth day, which was on a Tuesday, our clinic day. The following Tuesday coincided with a Muslim feast "Ketimo" so I could not go to the clinic. The following Tuesday was a public holiday and the fourth Tuesday the nurse responsible for "changing cards" (registration of newborns) was not at work. I became very worried because for four weeks I could not register my baby and she was also not weighed but my greatest worry was surrounded my daughter receiving many injections at one go. I feared that this would make her sick. Too many injections give a child trouble; it will have fever, swollen injection site and be restless due to the pain encountered. As clinic days go by without being registered, I became worried. I have seen babies receiving three to four injections at one go, two on the arms and one or two on the thigh(s). I cannot stand the site and the pain and suffering that this young one will undergo. When I was finally registered, on the 08.01.02, I reluctantly accepted the injections prescribed for me, as refusal would mean either being put aside by the nurses or receiving several shots during my next visit (SM003a).

10 The social relations of vaccination decisions

Women make decisions to attend (or not attend) the clinic not as isolated individuals, but within social relations that bring particular forms of advice and pressure to bear. These vary greatly depending on her social and marital circumstances, but there are also changes which occur in the course of a woman's childbearing life.

Thus women in their first pregnancies, especially if, as is common, they are only teenagers, frequently feel vulnerable and inexperienced. It is common for a woman in her first pregnancy to move to her mother's home for delivery and the first few months of her baby's life. In Tambasansang, this may mean moving to a village nearby, or across an international border; in Sukuta, it may mean moving within the town or, for recent immigrants, back to a rural village. There, someone else will help with the "nursing care" of the baby. It is rare for a first-time mother to do this on her own, unless she is older.

Frequently, then, it is in its grandmother's home area that a first child will receive its first vaccinations. In many cases, such grandmothers are influential in encouraging clinic visits. Thus one young mother in Sukuta described how when she had her first child at only 15, she stayed with her mother until the baby was 4 months old. Her mother "forced" her to attend clinic, alongside other health care advice (SM012). Another (SM015) had her first child while a schoolgirl, out of marriage, and was first taken to the IWC by her mother; she introduced her to the nurses and this made subsequent visits easy. Sometimes mothers-in-law play the

same role (e.g. TM008, TM0018). Mothers and mothers in law are also advisors when it comes to traditional medicines; advice that is not easy to refuse given the relations of generational authority in Mandinka compounds. Thus as one Tambasansang mother described: ‘The in-laws were very keen on using traditional herbs and medicines; I had to accept what is given to me for the child especially when it promotes health’ (TM0018). Women moving to Sukuta’s new settlements are sometimes given a foster mother who plays this role: e.g. SM004 on arrival to the new settlement of Sukuta Muritani, found that as part of the expectation that she would associate herself with the people in the area, a foster mother was identified with whom she could deliver and care for her baby.

With accumulating age and subsequent pregnancies, women frequently gain in confidence and are sometimes in a position to advise others. Such mothers tend to share advice and copy infant care routines from friends: whether massage, putting on talismen, copying other forms of protection, or attending clinic. The clinic itself becomes a learning place where women exchange advice and discuss infant care worries, at least with those they know well.

Away from their mother’s home, women also negotiate clinic attendance more directly with their husbands. Generally, within the gender relations of parenting a mother is expected to maintain responsibility for day-to-day infant care and minor ailments, whereas a father would be expected to muster financial and logistical help in the case of a serious illness or injury. Within such divisions, mothers tend to assume unquestioned responsibility for vaccination and routine clinic visits, and few fathers seem to become involved. Even though family planning services – to which most husbands are opposed – are also dispensed at the IWC, it appears that they do not question their wives’ attendance on these grounds. On the contrary, most seem to be supportive, and in several cases fathers have played a “backstopping” role, finding transport for a wife who cannot otherwise get to clinic, for instance. In a few cases, fathers have even used their authority to force attendance against a mother’s inclinations. Thus a woman in Sukuta (SM017) described how she was only 13 when she first married, to an influential religious scholar. Her baby was not taken to IWC between 6 and 10 months of age. She said: ‘I am afraid of going to the hospital; there is something in me that is pulling me down’. With her second child she was equally reluctant, but her husband would force her and there were instances when he would beat her because she did not attend clinic.

It is said by woman to be a common pattern for women to cease to take their child to the IWC when they become pregnant with the next, largely due to physical difficulties in travelling, but also to a sense that one has “moved on” from preoccupation with the babyhood of the previous child. A woman’s history of childbearing, and her experiences with her older children, also shape her perspectives on vaccination for her current child, whether positively or negatively. Thus one mother in Tambasansang (TM0012) had her first three children die aged about 2 years, first of measles, second of prolonged swelling at 2 years after circumcision, and the third aged 3. With her 4th child, as she put it, ‘I prayed reverently to God that this child be alive, but I also made sure to attend clinic regularly. I had bitter experience with my first three children who

died during infancy. Now with God's help I will do my best to let these ones be alive'. She thus attended regularly for her subsequent 3 children, despite being blind, and despite the long walk first to Basse and then Damphakunda.

11 Research engagements

Understanding the concepts and social relations of routine infant health care and vaccination provides an important context for understanding people's engagements with medical research. Here, we deal first with how people in Tambasansang experienced and reflected on the PVT, and then, more briefly, with how some similar themes emerged amongst people in Sukuta engaging with the birth cohort study.

11.1 Tambasansang villagers' experiences of the Pneumococcal Vaccine Trial

As the specific practices of the PVT engaged with these practices and concerns around infant wellbeing, and people's personal experiences in this respect, so this shaped people's engagement with the trial. Whereas MRC and health staff often perceive public engagement as a matter of trust and distrust, or as appreciating or rejecting scientific modernity, parents' narratives indicate how many people considered PVT engagement in terms of a balance of danger and benefit. The dangers principally concern blood taking, and the benefits the better or free treatments that people associated with MRC. Tambasansang, in this respect, may be slightly different from other villages in the PVT study area, as it has been involved in many earlier MRC studies. As we now illustrate, rather than people engaging with PVT on its own particular terms, many villagers framed their engagement with this trial in more general terms as "with MRC" as a health providing institution – which people join (sign up to? 'Trust?') in a way more akin to registering a child with the government health service, than to consenting to participate in a trial. This in turn may help contextualise some of the discrepancies between villagers' accounts and the formal protocol and procedures of the PVT, and more broadly might question how far any particular trial can set the terms in which it will be interpreted.

The dangers that people associate with MRC primarily revolve around blood-taking, and not the administering of a new product (trial vaccine). Several of the earlier studies which MRC had carried out in the village had involved blood-taking. For some, direct personal experience of this, in the context of broader worries about the effects of blood-taking, shaped their perspectives on the PVT. Thus one man who joined a 1978(?) study thought he had been chosen because his blood was amongst 'the best in the village'. He recalls how they tried to take a lot of blood, but after the first intravenous syringe-full he felt a pain in his chest and told them to 'stop or I will fight you'. He recalls no reason being given for the blood-taking, only that a promise of gifts of medicine failed to materialise: 'I received nothing, and felt very offended'. Furthermore while he initially thought the blood-taking was to help treat Gambians, as time went by he reflected that it was probably to treat Europeans, as 'African blood is stronger' than theirs. Another man had a child registered

with MRC earlier in the 1990s. He was sickly and had been visiting MRC frequently. The child was admitted and samples of blood were taken. Despite the treatment, the boy's father was not happy with the frequency and quantity of blood taken, and claimed to have stopped the MRC worker by threatening to fight him. This experience left an enduring sense of danger and disquiet, that 'MRC are attracted by my son's blood, because our blood is of higher quality than that of the white people'. Similar views recur in many interviews.

Less personal experiences still shape others' reflections on MRC as an institution. For example, when recalling an earlier MRC programme 'to promote child health', a group of men remembered how some people who initially joined the study withdrew as they were not pleased with the blood-taking, which left certain children weak, despite the reassurances and blood-replenishing medicine (*yello kafu boro*) which MRC provided. This fed a perception that this latest MRC programme would also involve blood taking. These men described how they waited and 'assessed the situation' before making a decision about trial registration (discussion with men, 15 May 2003).

People's experiences of laboratory practices also fuelled such anxieties. For example several women in the study village had been involved in a safety and efficacy trial (in 1998?) which preceded the PVT, in which they were transported to the MRC field station where blood samples were taken, before and after a trial injection. Here, as one of the participants described:

I witnessed an incident where a blood sample was taken from a baby, put in a small bottle and mixed with the *boro* [serum] in the laboratory. After it was mixed, the women who were present misinterpreted it to be whole blood withdrawn from the baby. This was circulated in the village and people were scared.

(Interview, mother, 15 May 2003).

When the full PVT began, this particular incident became a reference point for some of those who expressed reluctance to join the trial. It was used to justify fears that MRC takes large blood samples, for sale in London. It also demonstrates how easily exposure to laboratory research practices – a strategy MRC has on occasion attempted to use to allay people's anxieties by showing them what is actually done with their blood samples – may not have the intended effect.

The benefits that people associate with "joining MRC" to be gained are the reliable, good quality, free medical care for their children, themselves and in ambiguous ways, other family members. Thus whilst in the case of PVT, the formal trial protocol and procedures do not grant special treatment privileges to study subjects, there is a pervasive view amongst villagers in Tambasansang (also evident in other villages such as Gambisara) that joining MRC (joining the trial) does bring such privileges. Accounts variously draw on the benefits of free treatment, better treatment, more convenient treatment, greater availability of drugs, or of transport, and these all contribute to a view that joining MRC is good for people's health. For example, one woman, when asked what the PVT meant to her, said she could not recall what was said to her during the counselling session but 'one thing I know is that it offers good treatment leading to good health, and my

stepmother's children [registered with the trial] are doing well' (RG02).⁷ As another woman described, 'At outreach in Damphakunda, the nurses would not force anyone to register with MRC. They would say, "you are free to choose between two institutions. There is the government hospital as well as MRC"' (RT001).

Some accounts remain ambiguous about whether such benefits are restricted to study subjects, or whether are available more generally as a result of MRC visits in the area. However, other accounts are very clear about the distinction. For example, one man described how, in his view, MRC staff tried to encourage people to join 'through the provision of incentives and comparing the health of those who were registered and those who were not registered in the study' (RT004). A woman described how:

My husband allowed me to go to the MRC clinic, his peers would tell him they have very good medicines which saves time and money of going to Basse to buy the prescribed drugs. I also supported the idea, because I have observed that if one has an MRC card you are directed to go there by the staff of the government clinic when the baby is sick. In addition, special attention is given to you (TM004).

Or:

I have registered with MRC and has seen the benefits. One good thing about it is that, there is no money involved. The parents would also benefit from the treatment given. Drugs are so expensive and are not available in government hospitals so some have to accept the services of MRC that have been provided (RG05).

One of the few women in the village who appeared to conceive of MRC activities in terms of more differentiated trials described how:

In 1998, I was invited to joint a trial test on a vaccine for pneumonia, and I accepted due to the protection from pneumonia, and the free treatment from MRC. After this study, the general trial opened up and people started to register. Men changed their minds due to seeing the benefits of free treatment.

Given that Tambasansang has been a location for earlier studies with different protocols regarding treatment privileges for study subjects, there is clearly room for confusion between the practices of different trials, as well as for a general perception that all must be working in the same way. Some villagers' discussions turn less on whether or not different studies offer free treatment but on who precisely is entitled to this. For example, one elderly man perceived the PVT as restricting treatment to children, and resented this as a step backwards in MRC's overall goodwill towards the community as compared with earlier trials which, as he understood it, did treat wider family members. He interpreted this as a sign that the PVT was a less important programme, a

⁷ Interview codes prefaced by an "R" refer to narrative interviews focusing on people's research engagements ("research biographies") conducted in Tambasansang (RT), Gambisara (RG) and Sukuta (RS).

“winding down” after a long MRC involvement in the village where ‘surely MRC must by now have met its objectives’.

The practices women met at the monthly trekking clinic in Tambasansang once the PVT had begun appeared to them to reinforce the differences between being “with” and “not with” MRC, and the implications of these for infant care. Tambasansang and other villages within the catchment of the main Basse clinic differed in this respect from other areas of the PVT which did not experience such high attendance by MRC staff. In Tambasansang, the team of government nurses would now be preceded by an MRC Landrover containing a group of MRC fieldworkers and occasionally a doctor. The four lines that used to form in different parts of the clinic building – for initial registration, weighing, vaccinations, and antenatal checks – were now joined by a fifth, MRC line, under a tree on the other side of the courtyard. After their usual weighing, women would, if their infants were due, proceed to the vaccination table. During the stages of the trial when vaccines were being administered there would now be an MRC vaccination clerk working with the government nurse to ensure that the correct vials of trial or non-trial vaccine were given, but working together at the same table, they did not appear strongly distinct, enabling it easily to be taken that vaccinations were still something “of government” (which indeed they were, given that PVT is a joint MRC-Government trial). The spatially-separated MRC line, which was there primarily to screen children, was generally perceived by mothers as for treatment, and those registered with the PVT could queue there if they were concerned about their infants’ health. Here, they would have a consultation with a team consisting of a nurse, a fieldworker and occasionally a doctor. This appeared to women as a level of attention exceeding the quick advice they might receive from one of the government nurses, or the MCH trekking team. The MRC table had beside it a large trunk which appeared to women to be filled with drugs (even though it also contained documentation). In contrast, women suggested that the government team rarely had a wide selection of drugs available and would usually refer cases requiring treatment to the hospital in Basse, requiring a difficult half day’s walk or an expensive, and usually unavailable, taxi or trap. MRC take any seriously ill child that they encounter, whether a study participant or not to hospital. Nevertheless, some villagers considered this as a benefit reserved for study children, especially for more borderline cases. In general perception then, in Tambasansang at least, entitlement to join the MRC line represented not just “free” treatment, but on many occasions, any treatment.

On a clinic day that we observed, for example, a woman anxious about the rash on her two month old baby lamented the fact that he had just missed joining the PVT, for which registration closed a month before his birth. She tried queuing up at the MRC table, but was turned away as she was not a trial participant. Several other women had similar experiences, with children who fell either side of the trial age bracket. Seeing registered children and their siblings receiving medicines reinforced their sense of denied access to something which had become “normal” to many of their kin, friends and neighbours. The MRC staff did actually treat several non-registered people that day, including a very sick child and an elder. But they selected only serious cases, balancing their sense that ‘we can’t turn anyone away when there is no-one else’ and the need to

maintain overall community goodwill on the grounds that ‘everyone is a potential study participant’, with awareness that ‘we can’t treat everyone’. It is surely a difficult balance to strike.

How the potential benefits of “joining MRC” are assessed against anxieties or dangers involved clearly varied, and was often intensely discussed within families, drawing in wider members of the village. There was often a gender dimension to these negotiations. For example, the woman who observed the laboratory mixing of blood and serum went on to explain how it provoked ‘quarrelling between husbands and wives, because the husbands refused to let them join the MRC programme’. PVT registration was frequently an issue of tension between husbands and wives. While husbands often expressed concerns around MRC’s motivations and blood-taking, and shared these anxieties with others in the bantaba, it appears that women more often relegated these to the background in relation to their prior concern with day-to-day infant care.

Several cases in Tambasansang illustrate disagreements between husbands and wives as they weighed up benefits and dangers differently, and interpreted past events in different ways that justified their perspectives. Indeed in the single case in the village where PVT registration was eventually declined (TM007), this seems to have been the husband’s decision in the face of serious opposition from his wife. She is even reported to have considered registering behind his back, but was dissuaded by the Village Health Worker and several friends who advised that this would presage the breakdown of an already tenuous marriage. The disagreement, over registration of their 9th child for the PVT, went back to the couple’s experience with their fourth child. As the husband described in an interview with both present:

Initially, the child joined the MRC programme, during which period they were supplying things to encourage people into joining. They brought soap, powder during the naming ceremony. When he was sick, I took him to MRC and they took some blood from him, which contributed to the severity of his illness. He became very sick, his body was very hot, snot running out continuously and he died in the hot burning sun.

However, the mother attributed the child’s death differently, to an illness called pannuo which affects the fontanel. After MRC failed, as she described it, she took the child to Basse Health Centre, and then resorted to local treatment, but none was effective. While she justified the need for her children to join MRC and get “good medicine”, the father continued to stress his point that nothing would convince him about MRC. He said:

We have an option, that is the government clinic. The most that children suffer from is malaria and there are both local and traditional medicines. God will decide the fate of my children, I have been travelling to Basse to raise money, and I will continue to do for my children’s sake. I am concerned about my family’s health. But I have something inside me indicating that if I let my children join the MRC and there is a problem then the sin is between me and the child and I take the overall responsibility.

In another case (TM009) a woman's husband was a powerful marabout who "hated MRC programmes" although his wife could not say why. Their 5th child would have been eligible for the PVT, and she would very much have liked him to join as he was very sickly, suffering from multiple boils and frequent stools, but her husband refused so she was left to seek treatment at Basse health centre.

In some respects, it seems that MRC, in offering free, accessible treatment including for serious illnesses, is filling in what would normally be a father's role in an infant's health care: that is, stepping in with financial and logistical assistance with serious problems. From this perspective, it is not surprising that some men make a different calculus of benefit and danger, and welcome MRC health provision as "letting them off the hook". This is particularly the case for men who have travelled or outmigrated, whether to Banjul or abroad. Thus one woman (TM0019) registered her 3rd child for the PVT on the recommendation of the child's father, who stays in the Kombos. It seems that he saw MRC as a kind of insurance, in his absence: 'my husband asked me to go to MRC as they have good medicines. The father stays in the Kombos and if the child had an attack it would be difficult but with MRC one prevents as well as cures'.

The tenor and outcomes of such negotiations between husbands and wives were shaped by the practices associated with both the consent process, and with clinic attendance. People relate that it was women who were handed the PVT information sheet and consent form at their first clinic attendance with a new baby. Only an exceptional few could read the Arabic translation on the reverse, let alone the English explanation. Most brought them home to their husbands. However it appears that neither could many men read the explanations for themselves. Some did; others turned to a few literate individuals as interlocutors, but whether these did not translate the information sheets at all, or radically paraphrased them, it seems that the only message recalled from these sheets (by the husbands who can recall them, and some cannot, or had to be reminded of their existence by their wives) is that MRC was proposing "nothing bad" and that it would be "good to join". This was reinforced when, after many village men had discussed confusions over the meaning of the trial, consent, and signatures, the village head (Alkalo) called a meeting at which he and senior elders came to a village commitment that everyone should join.

This engagement with the consent form, in conjunction with the village meeting led many men to decide that their babies should be registered. Talking about this issue in a group discussion, women denied any power over such decisions; 'it is up to our husbands to decide'. In other words, where women are concerned the "informed consent" process is overshadowed by gender relations. Nevertheless, it is also the case that such decisions usually coincided with women's interests, so they had little reason to resist them. Where quarrels did arise – and there are many reports of heated ones – it is in those households where a man's resistance based on earlier experience, untempered by these ineffective practices of explanation through the consent form, clashed with a woman's interests in registering, largely to guarantee treatment for her infant.

Thus for many mothers in the village, enrolling "with MRC" was not primarily about "engaging with a trial"; nor was it seen as much to do with vaccines. Primarily, it was experienced as a route to better and

cheaper medical treatment. The trial's practices of surveillance were, for these women, felt more as practices of security, keeping a watchful eye on and providing a safety net for infants so extremely vulnerable to the exigencies of physical, social and spiritual life. And in seeking to have their children registered for these reasons, they frequently had to negotiate with husbands, compound heads and others whose differentiated experiences had shaped other concerns.

That, in the end, all but one eligible infant in the village was registered for the trial led to the village being labelled as “accepting” by senior MRC staff. There was therefore some surprise when an attempt to recruit a sample for a follow-up immunogenicity study encountered significant numbers of people who declined to participate. It also enabled a discursive contrast to be drawn with “refusing” villages, and particularly with those that had apparently mobilised to resist the vaccine trial. But as our account has shown, such dichotomous ascription of “accepting” or “refusing”, whether to individuals or communities, depends on a black-boxing of people's more varied experiences and concerns. What came to be construed as “acceptance” – the signing of the consent form, and a child actually having the vaccines – was often a negotiated path with worries along the way, involving struggles around gender, generation and authority; anxieties and struggles which were also ongoing in villages such as Gambisara but which played out in slightly different ways, to generate more apparent “refusals”.

Equally, casting people as accepting/refusing participation in a vaccine trial presupposes that they construed and experienced it as such. Instead, as we have tried to show, people are appropriating aspects of trial practice into their own experiential world and framing of infant care, its hazards and struggles. There are specific points of engagement, but these are of specific aspects of the trial, while others fade into the background as less relevant.

11.2 Sukuta parents' experiences of the birth cohort study

Similar themes emerge from parents narratives in Sukuta, where MRC also has a long presence. Indeed the current birth cohort study is the latest in a longer history of research practices in Sukuta, including a birth cohort study conducted over forty years ago. In 1960–62 David Marsden, a doctor based at MRC, conducted a study in Sukuta to ascertain the pattern of disease from birth to eighteen months, which involved identifying all the newborn babies seen at the Sukuta government clinic during a particular three month period, and tracking them until they were eighteen months of age. The study appears to have involved no formal consent procedures. It involved blood-taking: ‘Blood was removed from the internal jugular vein’ at the end of six months (1964: 460), and again from both mother and baby after eighteen months.

Today, despite the complex explanations and informed consent procedures, and despite the best efforts of MRC fieldworkers to explain the study in terms that mothers might understand, it seems from our narratives that mothers have only a rather hazy idea of what the current birth cohort study is about. However, this seems less significant to them than the capacity of MRC, as another health providing institution, to

provide good quality, free treatment, and thus assist with the general burdens of maintaining infant health in a hazardous world. Women's narratives also reveal how they have weighed up these benefits against dangers of MRC over the years of MRC presence; dangers either pressed upon them by husbands or compound elders, or that they have heard about as more widely circulating rumours.

Thus one older woman (SM004) described being part of a study 17 years ago.

My first child, a girl, was registered with MRC; she was booked immediately after delivery. The MRC staff were always on site to counsel women before and after delivery about the project and the need for one to join [although she could not recall the objectives of the project]. During that period everyone was registered. If you were not convinced about them they would register you and try to convince you and your husband. While some men would be convinced others would reject. During those days, when blood was taken from children, they suffered a lot. The women complained and the husbands intervened by either withdrawing their children from the study or refused children registering. MRC staff were very active and their relationship with people was very cordial. They brought incentives to attract people and people accepted. They will do home visit, meet and discuss with the couples, they will take you to the health centre when the need arose and ensured that you are brought home. People are gradually accepting MRC now, because they offer good treatment, whenever blood is taken, they ensured that enough medicines are given to replace the loss. They will never do what is bad (SM004).

Another woman (SM003a) was part of MRC research in 1993/94. She recalled how to motivate people to register with them, MRC provided rice, sugar, oil etc to study members. 'We were allowed to see them regularly or when ever the child is sick we would receive free and very good medicines. They would also do follow up visits to ensure that the child is well. They will take blood from them at least every three months and would give them medications to replace the blood loss'. She explained how, whenever MRC staff visited her or took some blood, some people would advise her to withdraw from the research, commenting that MRC steals blood and that they (mother and child) would be left short (yelo bee doya laa). While some withdrew, she continued as her child continued to receive prompt attention whenever they went to the main MRC laboratories in nearby Fajara.

Similar balancing emerges in women's narratives concerning the current birth cohort study. However, and in apparent contrast to women in Tambasansang, those in Sukuta revealed themselves as more influential over consent processes – and in a stronger position to evaluate, accept or reject the views of men and elders. Thus for example one mother perceived that 'the study is examining children for child sickness such as malaria, and this would entail blood taking'. She remembers being counselled by MRC staff a few hours before delivery but not recalling much, and then being counselled again after delivery, with her husband, and then accepting, when they accepted. She feels that:

Caring is much easier now I am registered with MRC, as MRC provides good medication for both child and parents. Although they have been associated with selling blood, I am convinced that the blood they take would not earn them so much money sufficient for daily living. Some have attempted discouraging me but I have not listened (SM004b).

Another woman (SM017) had her 5th child registered with MRC. She views MRC as positive, as another institution providing good treatment. She claims not to believe rumours about selling blood: 'They took a bit of blood from my son and I witnessed them testing it so the rumour about them selling blood was not true'.

Similarly, another woman, in Sukuta Muritani new settlement consented to join the study when she and her husband were asked. The main message she has retained from the explanation is that the research involves taking various samples from both mother and child, including cord blood, urine, sputum, and blood samples when the baby is 5 and 8 months old, as well as from the mother. She claims that:

Some elderly people discouraged us about the MRC programme but we did not listen. MRC has good drugs as opposed to the government clinic where you are asked to buy from a pharmacy. One good thing about registering with MRC is you are sure to have the required health care services, their staff will inform you when to attend clinic and you will also be given the required attention. Study subjects are given priority over others, as we are picked out from the lot, weighed, immunised and asked to go home. This saves us from the long queue as time saved will be best utilised for household chores. Whenever blood samples are taken, tablets are given to replace the loss. They also provide us with tablets for fever (if vaccinated).

As this narrative illustrates, women in Sukuta also regard the MRC study as having positive interactions with routine vaccination, helping their attendance and helping them to cope with side-effects. This is a longstanding association, which goes back to earlier studies. Thus one older mother (SM004), speaking of a study 17 years ago, described how:

During IWC days, they ensured that you attend or else they will pick you up from wherever you may be and will take you back after being treated. They ensured that their subjects do not default as vaccinations were always on time. MRC would provide medications especially for side effects resulting from vaccination. One unavoidable side effect was the pain leading to the persistent crying. If crying persists or the child is restless after vaccinations, the children are taken back to them and they would ensure that the mother came home satisfactorily.

SM003 had a baby registered with MRC in 1994. MRC staff ensured that she adhered to clinic schedules, for regular weighing and vaccination, accounting for complete attendance for this child.

Thus for women in Sukuta, MRC is seen and used primarily as part of routine health practices, and as a support to routine vaccination and clinic attendance. Indeed the integration between MRC studies and EPI is manifested in practices at the clinic, where MRC fieldworkers have been routinely helping to administer vaccinations, thus showing themselves to all who attend to be part of “normal” health practices, as well as (instead of?) part of an external “scientific” organisation.

12 Summary and conclusions

While the findings in this working paper are preliminary, and await to be complemented by a questionnaire survey, a number of conclusions can be suggested. Our approach has been rooted in the perspectives of medical anthropology and sociology of science, and in ethnographic methods. This has revealed a number of contrasts between the perspectives of health institutions and those of parents, whether regarding routine vaccination, or vaccine-related research.

Regarding routine vaccination, as we have shown a view current among health professionals is that vaccination acceptance is linked to favouring modern health care to the exclusion of “traditional” practices, and to recognising the importance of vaccination in terms of the capacity of vaccinations to protect against specific diseases. However, our ethnography shows parents to understand vaccination as one among many practices for promoting infant strength and health. It is not displacing other practices such as Islamic talismen, or ensuring correct reproductive behaviour thought to influence child health, but is a complement to them, and more significantly, conducted in relation to them. Vaccination less stands for biomedicine, then, than complements other therapeutic and protective forms. Parent’s understanding of the stages of infant growth and moments of a baby’s vulnerability, and their understandings of their own particular child in this respect, influence how they understand vaccinations to work, and their own calculations of appropriate timing. Regardless of whether people recognise particular links between diseases and vaccinations, the most fundamental value of vaccination that parents value is their promotion of strength and health in a generalised sense. In this people do not rigorously distinguish vaccinations as preventative as opposed to curative.

Second, high levels of vaccination attendance among Gambian mothers are often attributed to the popular view that infant welfare clinics have become attractive social occasions affording women festivity and solidarity. However, this research shows that while this may be true for some women, many others feel excluded from, or worried by this public display because of their social circumstances, the health of their infants, and the ways these attract moral condemnation. Moreover, as a crowded public place full of children, clinics are feared as attractive to “bad people” who use esoteric means to harm vulnerable children. That women attend in groups (and use protective charms) is as much linked to this, as to simple social enjoyment and practical health. Solidarity among some is felt as exclusion among others.

Third, academic analysis and clinic practices tend to distinguish between good compliant parents and defaulters who miss or mis-time vaccinations. Defaulters are seen as neglectful, whether due to ignorance or priorities misallocated to travel or trade. Our research, however, indicates that these mis-timings usually arise through a particular (often exceptional) circumstance which is then compounded by either fear of the effects that stacked up multiple vaccinations will have on their child, or fear of degrading treatment by clinic staff, or both. This train of events can affect anyone.

Fourth, academic and health worker analyses also tend to see compliance or default as a matter of a woman's own personal attitudes and beliefs. However our research shows how women negotiate clinic attendance as part of social relations with husbands and older female kin. Forms of advice and pressure vary over the course of a woman's childbearing cycle, with implications for whether, where and how often she attends.

Regarding research, similar contrasts emerge. First, when considering people's engagement with vaccine-related research, medical researchers and fieldworkers tend to conceive of their work as a separate research activity. However, our ethnography finds that people treat MRC studies less as a separate "scientific" activity and more as part of the nexus of normal health practices, with MRC one of a number of health providers.

Second, MRC fieldworkers focus on the process of informed consent, and tend to distinguish strongly between "acceptors" and "refusers". Acceptors are generally seen as having understood and appreciated study aims and procedures, whereas refusers harbour misconceptions – whether because they are ill-educated, "traditional", or exposed to inappropriate foreign ideas. Some are understood to refuse because they are too wealthy to be interested in the free treatment that rewards study participants. However our research finds that the informed consent process – and even wider communication processes specific to a trial – are relatively less significant, both because they are often overtaken by gender and power relations (e.g. mothers are told to join by their husbands or compound heads), and because whether or not the aims of a particular study are known is less significant to people's decisions than their longer-term experiences and perceptions of MRC as an institution.

Third, whereas MRC and health staff often perceive public engagement as a matter of trust and distrust, or as appreciating or rejecting scientific modernity, our narratives indicate how many people consider MRC in terms of a balance of danger and benefit – especially of blood-taking vs. "free treatment". There are strong social differences around gender, migration position and wealth in how people weigh up these dangers and benefits, and strong negotiations, even arguments, in families where people have different views. Study participation – or not – is an outcome of such circumstances and compound negotiations reflecting power relations, rather than being linked inherently to any particular category of person.

Put another way, casting people as accepting/refusing participation in a vaccine trial or medical research study presupposes that they construed and experienced it as such. Instead, as we have tried to show, people are appropriating aspects of study/trial practice into their own experiential worlds and framing of infant care,

its hazards and struggles. There are specific points of engagement, but these are of specific aspects of the research, while others fade into the background as less relevant. And these points of engagement are constituted through and shaped by interactions with particular fieldworkers. Looking at experiential engagement with medical research and vaccine trials in this way suggests a re-casting of the notion of “public engagement with science” to recognise it as rarely head-on: not an encounter between distinct bodies of knowledge/institutions, but a more partial, and shifting, engagement between constellations of practices framed within different life worlds.

Moreover a core problem with existing framings of parents’ accounts of vaccination practice and research participation is their focus on “the decision”; the moment of correct vaccination or of signing a consent form as if this was simply a “decision”, outside of the wider social world, and creating closure around the issue. This view, we have argued, is more a product of the imperatives created in the current operational management of health and research institutions than of attention to parents’ ambitions, issues and concerns. Debates about informed consent as an on-going process move some way toward addressing this, but still reflect the life worlds of the researcher and not the researched.

Thus our ethnographic approach is revealing diverse anxieties, dilemmas and discussions that surround vaccination and research participation; grey areas that have been overlooked when these issues are considered in the black and white vocabulary of attenders and defaulters, and acceptors and refusers. These dilemmas are often shared by people whether they end up “accepting”, “refusing” or “defaulting”, with final outcomes dependent as much on the circumstances of people’s lives and social relations as on any pre-formed attitude. A one-off act of acceptance is no guarantee of acceptance in future studies. These issues are key to any attempt to understand how vaccination practice and research engagement will unfold in the future, and how dialogue and practices around it might be improved.

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